DOCUMENT RESUME

ED 150 522 CG 012 189

AUTHOR Weinberg, Nancy; And Others
TITLE Counselling Concerns of the Person With Cancer.
PUB DATE 77
NOTE 17p.; Paper presented at the Annual Meeting of the American Educational Research Association (New York, N.Y., April 4-8, 1977)

EDRS PRICE MF-$0.83 HC-$1.67 Plus Postage.
DESCRIPTORS *Counseling Goals; *Death; *Financial Problems; *Medical Treatment; *Patients (Persons); *Personal Adjustment; Physicians; Questionnaires; Research Projects
IDENTIFIERS *Terminal Illness

ABSTRACT

This study asked outpatients with serious illnesses to identify concerns which are not being adequately responded to. Three major questions were addressed: (1) To what extent do the private office patients of an oncologist have concerns about their medical treatment, physical condition, financial expenses, family adjustment and personal coping? (2) To what extent do these office patients want to talk with someone about these concerns? (3) With what type of professional or nonprofessional would the office patients wish to discuss their concerns? Of 120 patients approached by the authors, 111 agreed to be questioned. The paper presents the data collected with discussion of its significance. (PFS)

**********
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
**********

ED150522

# COUNSELLING CONCERNS OF THE PERSON WITH CANCER

Nancy Weinberg, Ph.D.
University of Illinois
School of Social Work
and
Institute of Child Behavior
and Development

John D. Schmale, M.D.
Christie Clinic
Champaign, Illinois

Deborah L. Barrier
Graduate Student
University of Illinois

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Nancy Weinberg

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC) AND USERS OF THE ERIC SYSTEM."

U S DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

Presented at the Annual Meeting of the

American Educational Research Association

Meeting, New York: 1977

CG012189

Recently the terminally ill patient has received considerable attention. Past policies of not informing a person when he or she is terminally ill have come under sharp attack. Critics of these policies claim that patients have the right to be informed of their prognosis so that they may have the opportunity to complete their business and get ready for their death in a prepared and hopefully tranquil way (e.g. Kubler-Ross, 1969). Counsellors working with dying patients are trained to recognize the stages inherent in the dying process and to help the patients progress from one stage to another until they reach the stage of final acceptance.

Although counsellors are helping hospital in-patients to relize a more comfortable acceptance of death, counsellors are not being utilized to assist the private out-patient to live as actively and productively as possible during the progression of a terminal illness. A relatively long period of time may pass between being informed of a terminal illness and the actual point of death. Private out-patients who are aware that their time is limited face numerous adjustments such as: changes in physical health, pressures on family and social relationships, concerns about personal finances and medical expenses, and personal feelings about the many effects of their illness.

In contrast to services offered the hospital in-patient, the out-patient of a private physician is rarely offered any professional counselling. The private physician in office practice, a major source of support, has limited time to help the patient cope with non-medical concerns or adjustments. Family and friends do provide additional support and assistance, but it may be that many patients could benefit from further opportunities to discuss their feelings and to be informed of services relevant to their needs.

Traditionally, counsellors have not been employed in private office practices. This situation, however, is changing, and fortunately the number of counsellors associated with private office practices and group medical practices is growing slightly (Hookey, 1975). To further encourage this trend, documentation of the importance of counselling services for private patients is needed. It is, therefore, the intention of the authors to identify the concerns, if any, that the out-patient with a serious illness has which are not being adequately responded to. Three major questions were addressed in the research: 1) To what extent do the private office patients of an oncologist have concerns about their medical treatment, physical condition, financial expenses, family adjustment and personal coping? 2) To what extent do these office patients want to talk with someone about these concerns? 3) With what type of professional or nonprofessional would the office patients wish to discuss their concerns?

## METHODOLOGY

### Sample

The sample was defined as the private office patients seen by a cancer specialist over a ten-week period of time. Of the 120 patients seen by the physician, 111 patients agreed to participate. These included 72 females and 39 males between the ages of 19 and 84 with a mean age of 55. The entire sample was from the Central Illinois area. Approximately half came from cities with a population of over 20,000 and the rest came from more rural areas.

More than 75% of the sample were married and had at least three children, the majority of these children being over twenty-one. Only four patients had children under 12. A wide spectrum of educational levels was represented.

About 25% of the patients had not completed high school, 50% had continued through high school, and 24% had some education beyond high school.

At the time of interviewing only 32% of the sample were working. Of those not working, 25% were unemployed due to illness, another 21% were retired and 22% simply indicated that they were unemployed. Respondents were also asked to indicate their major occupation when working. By using Duncan's classification system to determine the social status of occupations, it was found that a broad range of occupational levels was represented. Thirty-five percent of the sample had lower status jobs below 33 on the Duncan Scale, 40% had middle level jobs between 33 and 60 on the Duncan Scale, and 9% had jobs that fell between 60 and 90 on the scale. The remaining 16% indicated that their main occupation was housewife, a status not rated by the Duncan Scale.

More homogeneity was found in the sample on religion. Ninety-one percent of the sample indicated that they were at least somewhat religious. Seventy percent indicated that they were Protestant; 17% noted that they were Catholic; and 9% gave Christian as their denomination. One percent were Jewish and the remaining 3% gave no religious affiliation.

Generally, the patients questioned were aware of their medical condition. When asked about their diagnosis, 97% of the sample either gave the specific name of the disease or simply said cancer. Although the length of time the patients had known their diagnosis varied, the majority had been living with their illness for quite a while. A small percentage, 11% of the sample, had known their diagnosis for only 3 months or less, 28% had known for 4 to 23 months, and 61% of the sample had known their diagnosis for a year or more. Although 93% of the patients had been hospitalized at least once, only 15%

had spent over six weeks in the hospital. Thus, the patients were most often living at home and seeing the doctor on a private out-patient basis.

Procedure

During a regular office visit, each patient was asked by the doctor to fill out a patient survey to determine the adequacy of current services and to see if the patients wanted any additional services in medical or non-medical areas. Once the patient agreed to participate, a graduate social work student went into the examining room to administer the questionnaire. Each patient had the option of either filling it out themselves or having it read to them. Thirty-one percent of the sample chose to have the questionnaire read, while the remainder of the patients filled it out on their own. In either case, the social work student stayed in the room and was available for questions.

Instrument

The patient survey used was developed and piloted over a three month period by the researchers. The six areas of concern covered by the questionnaire included: medical, physical condition, financial, family, personal adjustment, and transportation. These six areas were chosen after reviewing the literature on patient needs, meeting with professionals who work with patients who are seriously ill, and talking with patients themselves.

The first part of the questionnaire was divided into six sections, one for each of these areas of concern. For each area a fairly standard set of questions was asked. Table 1 presents the general format of these questions by showing the physical condition section as an example. Ordering of the type of people given in question 4 (see Table 1) was randomized across the sections and special categories of people were included when appropriate. For example, under financial concerns, a vocational counsellor, independent

financial counsellor, insurance agent, and lawyer were also presented.

TABLE 1

PHYSICAL CONDITION

1. To what extent are you concerned about physical changes that you may be experiencing? Are You: (Check one)

_____very much concerned _____somewhat concerned _____not concerned

If you checked "not concerned", please go to question 6.

2. How much would you like to talk with someone about these physical changes? (Check one)

_____very much _____somewhat _____not at all

If you checked "not at all", go to question 6.

3. What specific things would you want to talk about? _____

_____

4. What type of person(s) would you want to talk to about your physical changes? (Please check as many as you wish)

_____person with a similar illness
_____nurse
_____doctor
_____friend
_____psychiatrist
_____family
_____social worker
_____minister, priest, rabbi
_____boss or co-workers
_____other (Please add)_____

_____

5. To what extent have you had a chance to talk about your physical changes you may be experiencing? (Check one)

_____very often _____somewhat often _____not at all

6. With what type of person have you talked with most often about your physical condition?

_____

7. To what extent have they been helpful? (Check one)

_____very helpful _____somewhat helpful _____not helpful

8. Would you want to talk about any of the following: (check as many as you wish

_____concerns about pain
_____lack of energy
_____changes in your appearance
_____limitations on your household activities
_____symptoms of the disease (i.e. paralysis)
_____other (Please add) _____
_____loss of weight
_____drug addiction
_____limitations on your job activities
_____other people's responses to your physical changes
_____limitations on your reacreational activities

Findings

Data presented in Table 2 show the percentage of patients expressing concern about each of the six areas. As the data indicate, a substantial percentage of the sample were at least somewhat concerned about most of the areas covered in the survey. Eighty-one percent of the respondents indicated that they were either somewhat or very concerned about the effect of their illness on their family. Seventy-seven percent of the sample was at least somewhat concerned about physical changes and 67% of the respondents noted some concern about their personal adjustment. In addition 49% of the sample expressed some financial concerns, and 41% of the patients indicated that they had at least some concerns about unanswered medical questions. Transportation problems did not develop as a main issue, only 14% of the sample had any concerns about transportation.

TABLE 2

Percentage of Patients With Concerns
and the Percentage Desiring Assistance

| Area of Concern | Degree of Concern | | | Percentage of total sample wanting to talk with someone about their concerns |
|---|---|---|---|---|
| | Not Concerned | Somewhat Concerned | Very Concerned | |
| Effect on Family | 19% | 39% | 42% | 30% |
| Physical Changes | 23% | 49% | 28% | 61% |
| Personal Adjustment | 33% | 48% | 19% | 38% |
| Financial Concerns | 51% | 30% | 19% | 30% |
| Medical Questions | 59% | 35% | 6% | 38% |
| Transportation Problems | 86% | 13% | 1% | not obtained |

Contrasting the percentage of those concerned with the percent of people wanting to discuss their concerns with someone, an interesting finding emerged. Although a large percentage of the sample were at least somewhat concerned about family, physical condition, personal adjustment, finances and medical questions, as seen in Table 2, a much smaller percentage wanted to talk with someone about these concerns. Clearly, many patients had concerns for which they did not want any additional assistance. It was found that, in general, approximately 30% of the sample wanted to discuss their concerns. The only exception to this finding was in the area of physical changes where 61% of the sample expressed a desire for help.

The question then arose whether the general figure of 30% represented many different people wanting to talk about several areas or the same 30% expressing a desire to discuss concerns in a number of areas. Further analysis revealed that in fact many different people were expressing a desire for assistance. Eighty-eight percent of the sample wanted to talk with someone about at least one area. Only 6% of the sample noted that they wanted to discuss concerns in five areas. Thus, it appears that individual patients had very diverse concerns.

Investigated next were the particular issues within each of the categories of concern that patients wished to discuss. As part of the questionnaire, patients had been given a list of specific topics of potential concern and asked to check as many as they thought would be useful to discuss. Table 3 presents the percentage of patients checking each item.

TABLE 3

Percentage of Total Sample Wishing to Discuss Particular Topics

| | |
|---|---|
| **Medical** | |
| effectiveness of treatment | 34% |
| side effects of treatment | 30% |
| cause of your illness | 24% |
| different types of treatment | 21% |
| waiting before you see the doctor | 6% |
| help with medical care at home | 4% |
| appointment system at the clinic | 3% |
| relationship with the doctor | 3% |
| having more time with the doctor | 2% |
| waiting room arrangement at the clinic | 1% |
| possibilities of going to a nursing home | 1% |
| treatment by medical staff | 0% |
| **Physical Condition** | |
| lack of energy | 44% |
| concerns about pain | 22% |
| limitations on your recreational activities | 22% |
| limitations on your job activities | 20% |
| limitations on your household activities | 19% |
| changes in your appearance | 17% |
| loss of weight | 16% |
| symptoms of the disease (i.e. paralysis) | 13% |
| other people's responses to your physical changes | 10% |
| drug addiction | 6% |
| **Financial** | |
| the American Cancer Society | 24% |
| your health insurance coverage | 13% |
| Medicare, Medicaid | 12% |
| dealing with insurance companies | 10% |
| paying for medication | 10% |
| wills | 10% |
| what if you can't pay medical bills | 10% |
| additional insurance | 6% |
| paying for hospital bills | 4% |
| **Family** | |
| feelings about your family's future | 26% |
| your ability to do things with your family | 14% |
| changes in how close you and your family are since your illness | 13% |
| your ability to talk with your family | 11% |
| feelings that you have let your family down | 8% |
| feelings that the family has let you down | 3% |
| **Personal** | |
| feelings about your ability to continue your daily work or activities | 29% |
| changes in your plans or goals as a result of your illness | 23% |
| fears about your illness | 21% |
| feelings about yourself since you became ill | 14% |
| feelings about your sexual activities | 14% |
| concerns about death and dying | 13% |
| feelings of disgust | 10% |
| spiritual or religious concerns | 9% |
| feelings of guilt | 4% |

As presented in the table, approximately 30% of the patients indicated that in the medical area they were most interested in learning more about their treatment, particularly how effective they could expect it to be and what side effects they could expect. Under the category of physical condition, concern centered around the patients' lack of energy and the consequent limitations of their activities at home, on the job and in recreational activities. Financial concerns that patients wished to discuss involved finding out more about potential sources of financial help. In the family area, patients were most concerned about discussing their feelings about their family's future. The patient's ability to do things with the family and changes in how close they are to their family were also checked as topics patients wished to discuss. The personal concerns patients wanted assistance with invloved feelings about their ability to continue their daily activities and changes in their plans or goals that had occurred as a result of their illness. In addition, a number of patients wished to discuss their fears about their illness, changes in feelings about themselves, feelings about their sexual activities and concerns about death and dying.

Patients were also given an opportunity to add additional concerns not listed, as well as to state their concerns in their own words. Reviewing the responses in the medical area, a reccurring theme was "What can I expect?" Some examples of typical comments were: "What symptoms should I expect if there is a reoccurrence?" "What can I expect to happen to me during the treatment I am receiving?" "How long will treatment continue?" "Is there a certain time I have to live?" "When it comes close to the end, what will happen--will something specifically fail to function in my body?" The second major thread in patient comments was related to treatment questions. For example:

"Will chemotherapy be successful?" "Why do they take a blood test every week?" and "How far has the cancer spread?"

When asked to enumerate the things they would like to discuss regarding their physical condition, most patients listed specific physical symptoms. The most common physical complaints people wanted to discuss were hair loss, sexual impotency, weight problems, weakness, and soreness or pain. Again a recurring question was: "What can I expect?" Here their uncertainty involved questions of what their physical abilities would be in the future.

Concerns about the future were also evident when the patients specified things they wanted to discuss in the financial area. Examples here included: "How much longer will Medicare cover my illness?" "How long will my money hold out?" "Will my insurance be enough to cover what comes later?" "Will my insurance be cancelled?" "What about my future insurability?" In addition, the patients seemed to want information about financial help and about particular programs such as Social Security, disability insurance, major medical and Medicare.

In the area of family concerns, the patients were most concerned about the effect of their illness on their children. For parents with grown children the concern was how their children would adjust to their illness and for those with young children the concern was how they could manage their children. As the young parents put it, "How can I get my 13 year old son to accept my illness without worrying him?" For another parent the concern was, "How can I discipline my children and have them mind, as I do not have the strength that I used to?" When the children were grown, the worry was expressed in this way, "I don't want to be a burden to them (children)." Husband-wife role relationships were also of some concern. Husbands wanted to discuss their feelings about

staying at home while their wives worked, and wives were concerned about performing their usual household tasks.

In the area of personal concerns, patients seemed to be concerned about their adequacy to perform as they had before. They asked questions such as "Will I be able to walk around and do things for myself and my family?" or "Will I be able to continue working?" Emotional adequacy was also a major concern. As the patients put it, "Can I maintain a reasonably stable outlook as the disease progresses?" "How can I keep from becoming depressed?" "Will I pull away from things because of my illness?" A dislike of their dependency and loss of control also seemed to be a strong concern for many patients. As one 40 year old man said, "It puts a bigger load on my wife; my children go to my wife to ask for things; my wife is taking over everything, including driving." Finally there was again a concern about the future, "What does the future hold and how should I approach it?"

From what professional or nonprofessional the patients wanted assistance was the next question addressed. A mean rank score was obtained for each type of helper based on how frequently he or she was mentioned as a person who could be of assistance.

Highest ranked, or the helping person named most often was the doctor. The physician was named most frequently as the person from whom the out-patient wanted help about medical questions, physical changes, family matters, and personal adjustment. The one area in which the doctor did not rank first was financial concerns. In this category he received a two, giving him a total rank score of 1.2.

Second ranked with a total score of 2.2 was a person with a similar illness. Next to the doctor, other people with cancer were seen as most helpful to talk

with about family problems, physical condition issues, and medical concerns. The family ranked next with a rating of 2.8. The family was viewed as the most helpful for talking about financial concerns but in terms of discussing personal adjustment it was second and for family matters it was ranked third. Nurses received the next highest rank of 4.4, friends obtained a rank of 5, ministers received a rank of 5.2 and social workers ranked 6.4. The two other types of helping persons listed on the questionnaire, psychiatrist and co-worker, received ratings of 7.7 and 8.2 respectively.

Examining these data, it should be noted that any generalization of the finding that the doctor ranked first as a helping person is very limited. Since all of the patients were ranking the same doctor, it was difficult to know whether it was the strength of this particular doctor that gave him a high rank or whether all doctors would be perceived in this manner. More generalizability is possible from ranks received by other helping persons as in these instances, a variety of persons or images of persons were being rated. In this regard, it is particularly interesting that a person with a similar illness was seen as so valuable. This finding offers strong support for the movement toward self-help groups. Apparently, efforts to set up special groups of cancer patients or one-to-one interactions between persons with cancer would be positively received by patients.

It might be that people with a similar illness are particularly facilitative because they help other patients cope with uncertainty. Another cancer patient who has been ill longer can tell what they are going through and/or went through in terms of physical symptoms, personal concerns and social issues. Although the patient listening realizes that his or her medical case and life situation is not the same, it does offer them at least one view of

the future not available from any other sources. The importance of this type of information for the cancer patient also has some implications for counselling. It suggests that counsellors should be very knowledgeable about and at times make reference to situations of other cancer patients. In this way counsellors themselves can help patients have access to the kind of information they seek.



NW:1a

REFERENCES

Kubler-Ross, E. On Death and Dying. The MacMillan Company, New York, 1970.

Hookey, P. G. Social Work in Primary and Ambulatory Health Care: Access, Utilization, Attitudinal and Economic Aspects of an Emergent Field of Practice. Unpublished dissertation. Washington University, St. Louis, Missouri, May, 1976.

FOOTNOTE

The authors wish to thank the following people for their invaluable assistance: Kathy Apple, Paula Auerbach, Cheryl Berger, Helen Birky, Carolyn Dunham, Jim Jorden, Charles Kramer, Barbara Nebeck, William Pearse, Valerie Sexton, Jacqueline Sofo, Toni Stone and Kay Wright.